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Prenatal Genetic Screening: The Enigma of Selective Abortion

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PRENATAL GENETIC SCREENING: THE ENIGMA OF SELECTIVE ABORTION

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In the survival of favoured individuals and races, during the constantly-recurring Struggle for Existence, we see a powerful and ever-acting form of Selection . . . Thus, from the war of nature, from famine and death, the most exalted object which we are capable of conceiving, namely the production of the higher animals, directly follows.

Charles Darwin, ORIGIN OF SPECIES

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And I think that our braver and better youth, besides their other honors and rewards, might have great facilities of intercourse with women given them; their bravery will be a reason, and such fathers ought to have as many sons as possible.

Plato, THE REPUBLIC, Book V, 460b

I. INTRODUCTION

As we near a new millennium, technology changes the world at an astonishing rate. Almost no aspect of our world is as it was only a few years ago. Included within this change is the advent of new reproductive technologies which influence the choices available to prospective parents.

Among these new technologies is the ability for science to accurately predict the genetic make-up of a fetus.[2] Available methods obtain samples of pre-natal cells and perform a battery of genetic testing.[3] Advances in molecular biology and genetics will soon produce a "genetic map"[4] which prospective parents can use to assess a full complement of the genetic traits of a potential child.[5] The advent of these technologies also brings questions of whether this "science" is ethically and legally acceptable.[6]

This paper examines the issue of pre-natal genetic testing and its ethical and legal concerns. Part II details the scientific techniques involved in pre-natal genetic testing. Part III discusses the Human Genome Project and its influence on the choices available to prospective parents. Part IV analyzes the moral and ethical issues raised by pre-natal genetic screening. Part V presents the legal issues raised by pre-natal genetic screening. Finally, Part VI concludes and offers a prospective on the future of these technologies.

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[2]Dorothy C. Wertz, *International Perspectives on Ethics and Human Genetics*, 27 SUFFOLK U.L. REV. 1411 (1993); Kimberley Nobles, Note, *Birthright or Life Sentence: Controlling the Threat of Genetic Testing*, 65 S. CAL. L. REV. 2081 (1992).

[3]Michael J. Malinowski, *Coming into Being: Law, Ethics, and the Practice of Prenatal Genetic Screening*, 45 HASTINGS L.J. 1435 (1994); Vicki G. Norton, Comment, *Unnatural Selection: Nontherapeutic Preimplantation Genetic Screening and Proposed Regulation*, 41 UCLA L. REV. 1581 (1994).

[4]Julia Walsh, *Reproductive Rights and the Human Genome Project*, 4 S. CAL. REV. L. & WOMEN'S STUD. 145, 146-48 (1994).

[5]The Council on Ethical and Judicial Affairs, American Medical Association, *Ethical Issues Related to Prenatal Genetic Testing*, 1994 ARCHIVES FAM. MED. 633, 638 [hereinafter AMA].

[6]*Id.* at 635.

II. SCIENTIFIC TECHNIQUES

A. Amniocentesis

Amniocentesis allows doctors to withdraw fluid from the amniotic sac and harvest the fetal cells contained therein.[7] This is accomplished by piercing the abdomen of a pregnant woman to gain access to the amniotic sac. A portion of the amniotic fluid is withdrawn and incubated to increase the concentration of the fetal cells found in the amniotic fluid.[8]

One of the major drawbacks of amniocentesis is that it cannot be performed before the fifteenth or sixteenth week of pregnancy. Adding the time for incubation of the cells, the earliest an expectant mother can learn the results is around nineteen or twenty weeks. Additionally, amniocentesis has resulted in approximately a 0.5 percent pregnancy loss in the United States.[9]

B. Chorionic Villi Sampling (CVS)

CVS extracts fetal cells through biopsy of the chorionic villi.[10] The chorionic villi are hair-like projections that surround the embryo in the early stages of pregnancy. CVS can be performed by a physician using ultrasound to guide a thin catheter through the cervix. Once in the uterus, a small plug of tissue is removed. This plug contains chorionic villi from which fetal cells can be harvested.[11]

The major advantage to CVS is that the procedure can be performed within the first three months of pregnancy. Because the chorionic villi will disappear in later stages, this procedure must be performed before the tenth week of pregnancy. CVS has the additional advantage of needing no time for incubation of the fetal cells. Thus CVS provides patients quicker results than amniocentesis.[12] However, the incidence of pregnancy loss as a result of CVS is slightly higher than that associated with amniocentesis.[13]

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[7]John T. Hansen & John R. Sladek, Jr., *Fetal Research*, 246 SCIENCE 775 (1989).

[8]*Id. See also* Laurence E. Karp, *The Prenatal Diagnosis of Genetic Disease, in* BIOMEDICAL ETHICS 458 (Thomas A. Mappes & Jane S. Zembaty eds. 1981).

[9]Hansen & Sladek, *supra* note 7.

[10]Gina Kolata, *First Trimester Prenatal Diagnosis: A New Method of Prenatal Diagnosis May Largely Replace Amniocentesis*, 221 SCIENCE 1031 (1983).

[11]*Id.*

[12]*Id.*

[13]Hansen & Sladek, *supra* note 7. This procedure is not seen as a complete replacement for amniocentesis because it cannot diagnose neural tube defects. These types of defects result in diseases like spina bifida as a result of a failure of the neural tube to close completely before birth. In addition, the incidence of damage caused to the fetus as a result of this procedure is slightly higher than that found with amniocentesis. Kolata, *supra* note 10.

C. *In Vitro Fertilization*

In in vitro fertilization, sperm and egg samples are artificially conceived outside of the womb.[14] Once conception occurs, the resulting zygote begins to divide. At the eight cell stage, a single cell can be removed and genetic screening can be performed.[15] Once the cell is removed, the zygote can be frozen awaiting the results of a genetic screening. If the resultant screening shows that the zygote has no genetic diseases, it can be implanted into a woman and carried to term.[16] Because the rate of successful pregnancies per implanted egg is relatively low,[17] multiple zygotes are often implanted during each separate procedure.[18]

III. THE HUMAN GENOME PROJECT

The Human Genome Project is a worldwide effort to completely map and sequence the entire human genome.[19] The Project began in the United States in 1989 and continues running in laboratories throughout the country. The project is expected to last up to fifteen years. Current funding for the project is near $200 million per year.[20] Of this expenditure, three percent is spent on funding discussions into the ethical and social implications that have and will result from the project.[21]

The goal of this project is to sequence each of the 50,000 to 100,000 genes found on the twenty-three pairs of chromosomes that comprise the human genome.[22] Once the project has sequenced and mapped each chromosome,

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[14] Norton, *supra* note 3, at 1592-6.

[15] This procedure is accomplished through the use of a microscope, vacuum and a glass needle to extract a cell from the zygote. *Id.* at 1594.

[16] This entire process is known as "Blastomere Analysis Before Implantation" or "BABI." *Id.* at 1593.

[17] *Id.* at 1596.

[18] This list of prenatal testing techniques is by no means exhaustive; two other methods deserve mention. First is Florescent In Situ Hybridization (FISH). This technique is performed at about the same time as amniocentesis, however its application to the subject of this paper is limited. The technique allows scientists to "probe" a child's chromosomes for genetic diseases with locations. *See* Leslie Roberts, *FISHing Cuts Through the Angst in Amniocentesis*, 254 SCIENCE 378 (1991). The other technique is fetal blood sampling. Because of the inherent dangers using this technique, its application is minimal. *See* AMA, *supra* note 5, at 633, n.14.

[19] James D. Watson, *The Human Genome Project: Past, Present, and Future*, 248 SCIENCE 44 (1990).

[20] Francis Collins & David Galas, *A New Five Year Plan for the U.S. Human Genome Project*, 262 SCIENCE 43 (1993). *See also* Watson, *supra* note 19.

[21] This program is referred to as "ELSI," (Ethical, Legal and Social Implications). Collins & Galas, *supra* note 20.

[22] Ulf Landegren et al., *DNA Diagnostics - Molecular Techniques and Automation*, 242 SCIENCE 229 (1988). Human genetics involves several levels of specialization. Every

scientists will have a guide that will allow them to know where each gene is located and what is the "normal" sequence of that gene.

This map can then be used as a measuring stick against which prospective parents can compare their potential children.[23] This map will be beneficial in that it will allow prospective parents to determine whether their children have any of the 5,000 diseases believed to be linked to genetic malformities.[24] However, the map's benefits must be weighed in light of other information that it will divulge. This information deals with non-disease traits that involve the more aesthetic details of being human.

IV. ETHICAL ISSUES

As the Human Genome Project moves closer to a completed map of the human genome, more and more links will be made between specific genetic compositions and resulting external physical traits and genetic diseases.[25] As this information becomes available to the public, an increasing number of parents will likely wish to have their potential children screened. In addition, physicians worried about malpractice claims based on wrongful life, wrongful birth, and wrongful pregnancy will likely increase the number of patients that they recommend should take these tests.[26] This increase in use of these procedures will create a number of ethical issues which must be addressed.

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human receives one copy (allele) of each gene from each parent. Each gene is located in a particular area on a particular chromosome. "Sequence" refers to the exact chemical composition of a gene. Through DNA sequencing technologies, the Human Genome Project will be able to determine the entire sequence of every gene on every human chromosome.

[23]George J. Annas, *Mapping the Human Genome and the Meaning of Monster Mythology*, 39 EMORY L. J. 629, 635-39 (1990).

[24]C. Strong, *Tomorrow's Prenatal Genetic Testing*, 1993 ARCHIVES FAM. MED. 1187, 1188. The majority of the 5,000 genetically linked diseases have not yet been mapped to a specific location on a chromosome. Victor A. McKusick, *The Human Genome Project: Plans, Status and Applications in Biology and Medicine, in* GENE MAPPING: USING LAW & ETHICS AS GUIDES Ch. 2 (George J. Annas, et al. eds., 1992) [hereinafter GENE MAPPING]. *See also* Iordanis I. Arzimanoglou & Fred Gilbert, *Genetics and DNA Technology*, 1994 CURRENT OPINION IN OBSTETRICS & GYNECOLOGY 445, 447.

[25]Malinowski, *supra* note 3, at 1481-85. Although the human genome map will theoretically provide this information, not every "difference" in sequence translates to a specific problem. Because of the influence of environmental factors and other genes, prediction of the onset of disease based on genetic testing is not an exact science. *Id.* at 1485-9.

[26]Lori B. Andrews, *Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks*, 29 HOUS. L. REV. 149 (1992). In her work, Andrews describes a physician's duty to warn a patient of potential genetic risks that may be faced by pregnancy. The advent of new reproductive technologies has resulted in new testing procedures that will allow physicians to screen pregnancies for genetic deformities. If the physician does not prescribe such procedures for patients, the physician is at risk of being sued for malpractice where a child is born with a disease that could have been tested for before the patient's opportunity to legally obtain an abortion ended.

A. Eugenics

The term "eugenics" was first described by Sir Francis Galton.[27] The term was used to refer to the belief by certain scientists that socially undesirable traits such as disease, poverty, and criminal tendencies were linked to an individual's genetic make-up.[28] Eugenicists used this theory to support their belief that persons exhibiting such traits should not be allowed to reproduce. These scientists believed that such a practice would lessen the impact and scourge of the underclass on modern society.[29]

1. Types of Eugenics

There are two categories of eugenics. The first is positive eugenics. This category involves genetic screening and use of the results to fix any problems evident from the procedure.[30] In other words, where the genetic screening manifests a problem, the problem can be fixed by genetic manipulation of the embryo or fetus to correct the problem. Even with all of the surges in technology, this process is still some time away from practical application.[31]

Negative eugenics, the second category, involves testing for the genetic make-up of the individual and then using the results to determine whether that individual should be carried to term or aborted.[32] The eugenicists believe that if individuals with problematic traits are not born, the traits will disappear through the use of "selective abortion."[33] It is this category of eugenics which this paper seeks to explain and analyze.

2. Government Attempts at Eugenic Control

Different governments have attempted to institute eugenic control programs in an effort to "better" their genetic pool.[34] These efforts have even been exercised in the United States. Eugenic scientists influenced Congress to severely limit levels of legal immigration in the 1924 Immigration Restriction

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[27] John R. Harding, Jr., Comment, *Beyond Abortion: Human Genetics and the New Eugenics*, 18 PEPP. L. R. 471, 480 (1991).

[28] Daniel J. Kevles, *Vital Essences and Human Wholeness: The Social Readings of Biological Information*, 65 S. CAL. L. REV. 255, 259-65 (1991).

[29] Harding, *supra* note 27, at 480-83.

[30] *Id.* at 478.

[31] *Id.* at 476-78. *See also* Walsh, *supra* note 4, at 149-151 (discussing the potential benefits of genetic manipulation on cystic fibrosis sufferers).

[32] Harding, *supra* note 27, at 478.

[33] *Id.* at 481.

[34] *See generally* Robert N. Proctor, *Genomics and Eugenics: How Fair is the Comparison?*, *in* GENE MAPPING, Ch. 4, *supra* note 24; Harding, *supra* note 27; Kevles, *supra* note 28.

Act.[35] The eugenic scientists were able to persuade Congress that much of the crime and poverty in the United States could be avoided by limiting the immigration of persons from Eastern Europe who were the purported "carriers" of these genes.

In *Buck v. Bell*,[36] the Supreme Court upheld a Virginia law that allowed forced sterilization of persons in state custody who had hereditary forms of insanity or imbecility. The state believed that it had an interest in stopping reproduction of genetically diseased individuals who it believed were taxing state resources. The Court upheld the statute by reasoning that such measures were an adequate exercise of state powers and were not contrary to patient's Fourteenth Amendment Due Process guarantees. Speaking for the majority, Justice Holmes wrote "three generations of imbeciles is enough."[37]

In *Skinner v. Oklahoma*,[38] Oklahoma's forced sterilization law for "habitual criminals" was challenged. The defendant challenged the law on grounds that it violated the equal protection clause of the Fourteenth Amendment. He claimed that there was no empirical evidence correlating the commission of certain crimes with the incidence of producing children with criminal tendencies. The Court found the statute to be a violation of the Equal Protection Clause because the application of the statute did not have an adequate factual foundation.[39]

The country of Singapore is an example of current government sponsored eugenic control.[40] The government has created a program whereby the most desirous women are actively courted to participate in programs that seek to

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[35]Ch. 190, 43 Stat. 153 (1924). This Act reduced the levels of legal immigration to the United States by about ninety-five percent. Before the Act was in place, the number of legal immigrants was set at 435,000. After the Act, this number was reduced to approximately 25,000. Proctor, *supra* note 34.

[36]274 U.S. 200 (1927).

[37]*Id.* at 205-7. The reasoning the Court used to uphold Virginia's statute in *Buck* legitimized other state's efforts to enact statutes that restricted other individuals' procreative freedoms. In his article, Proctor stated that over 50,000 forced sterilizations had been performed in the United States by the end of World War II. In addition, other indirect methods of eugenics were practiced in the United States. Most notable were the anti-misogyny statutes which restricted marriages between persons of different races. Proctor, *supra* note 34.

[38]316 U.S. 535 (1942).

[39]*Id.* at 541-43. In its decision, the Court discussed how the application of the Oklahoma sterilization law resulted in inconsistent outcomes. The Court compared an individual who had committed crimes that did not qualify for forced sterilization with *Skinner*. The Court found that the Oklahoma statute's application had absolutely no basis in fact because Oklahoma could not show how an individual like Skinner could pass criminal tendencies to their children while another criminal who was not considered a "habitual criminal" would not pass these criminal tendencies.

[40]*See* RUTH F. CHADWICK, ETHICS, REPRODUCTION AND GENETIC CONTROL 164 (1987).

match these high caliber women[41] with men of similar talents. The program involves government sponsored gatherings where these individuals can meet and even provides benefits to a couple who marry as a result of meeting at one of these gatherings.[42] The hope of this program is to keep the best reproducing with the best and not to "waste" this potential by allowing the educated to reproduce with the uneducated.[43]

3. Therapeutic and Non-Therapeutic Traits

One of the most pervasive ethical issues raised by the availability of pre-natal genetic screening involves the types of traits these procedures can identify. The question we must answer here is whether it is ethically acceptable for parents to choose to have an abortion based on seemingly small or treatable problems that a fetus may have. To resolve this question, we must distinguish therapeutic traits from non-therapeutic traits.

Therapeutic traits are described as those traits which result in disease in the human body.[44] These traits fall in a range from the most severe genetic deformities which will severely affect the lifestyle of a potential child, to diseases which can be controlled, to late-onset diseases.[45]

Non-therapeutic traits are those which have little relation to the health of an individual.[46] These include cosmetic features, athletic abilities and talents. Although many of the specific genetic sites that determine these features are not known, it is certain that the Human Genome Project will soon illuminate this information.

The real fear of negative eugenics comes into play in a discussion of these different traits. Many agree that abortion decisions based on severe genetic

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[41] The government is generally interested in highly educated women who are single after completing their education. *Id.*

[42] These benefits include tax rebates, preferential school placement for any children that result from the marriage and help with a down payment for living quarters. *Id.*

[43] *Id.* No discussion of government sponsored eugenic control would be complete without mention of Nazi Germany. During the period when Hitler was controlling Germany, many horrific human experiments were performed on unwilling subjects. In addition, severe restrictions were placed on couples' abilities to obtain marriage licenses. Finally, the German government sponsored huge programs aimed at the systematic murder of persons it considered undesirable to Germany (e.g. Catholics, Jews, Gypsies, and the mentally disabled). *See* Proctor, *supra* note 34.

[44] Norton, *supra* note 3, at 1588-92.

[45] Strong, *supra* note 24, at 1188. Examples of severe genetic diseases include muscular dystrophy and cystic fibrosis. An example of a controllable genetic disease is phenylketonuria (PKU). An example of a late-onset disease is Alzheimer's disease. Also worth mentioning is the capability of detecting genetic susceptibilities to diseases. This is important with diseases which are greatly influenced by the environment such as diabetes, cancer and heart disease. *Id.*

[46] Norton, *supra* note 3, at 1588-92.

defects are ethically acceptable.[47] Agreement slowly slips away as the major defects begin to become classified as treatable or minor defects. For example, there is a real question about whether we are willing to accept selective abortion decisions where the genetic screening shows that the child has a treatable genetic disease. Or, situations where a child inherits only a genetic susceptibility to a disease. Or, a case where the child will inherit the gene responsible for a late-onset disease such as Alzheimer's disease. In addition, we must confront the issue of whether we are willing to accept abortion decisions based solely on the non-therapeutic traits described above.

Because none of these choices are constrained by existing case law, statutory law or professional regulations,[48] the offering of these services is left to the individual physician.[49] In many ways it is the physician's own ethical views that will shape the types of services that are provided and the ability to obtain abortions based on testing results.[50] Dr. C. Strong has suggested that physicians who offer these services fall into one of the following categories: (1) those who will restrict pre-natal genetic screening to only the most severe disorders; (2) those who will offer pre-natal genetic screening for all but the most minor diseases; (3) those who will offer pre-natal genetic screening for all diseases but not for therapeutic traits and (4) those who will honor pre-natal genetic testing for any trait or disease.[51]

As these choices suggest, there may be wide disparity in the choices one physician may offer as compared to those of another. The situation boils down to the proposition that prospective parents will most likely be able to find a physician or clinic that can meet their needs and desires even where other physicians and clinics cannot. Physicians will be known by the choices they offer their patients and parents will choose a physician accordingly. Absent any regulation on the type or depth of pre-natal genetic screening that can be performed, the choice will be left to the physician. As Strong points out, the role of the physician should be non-directive.[52] However, it is impossible for the physician to be non-directive where the physician's decision actually restricts the parent's choices.

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[47] John A. Robertson, *The Potential Impact of the Human Genome Project on Procreative,* GENE MAPPING Ch. 13, *supra* note 24; John A. Robertson, *Procreative Liberty and Human Genetics,* 39 EMORY L. J. 697, 711 (1990); Strong, *supra* note 24, at 1188. *But see* AMA, *supra* note 5, at 635.

[48] Norton, *supra* note 3, at 1613-19; Strong, *supra* note 24, at 1192.

[49] Strong, *supra* note 24, at 1191-92.

[50] *Id.* at 1189-91.

[51] *Id.*

[52] *Id.* at 1189. The non-directive approach is one where "counselors attempt to avoid imposing their personal view on the patient." Strong, *supra* note 24, at 1189. The real question raised by this approach is whether patients can truly make autonomous decisions where their choices will be "screened" by a health care provider.

4. Sex-Selection

This ethical issue is an extension of the discussion above. Clearly, sex is a non-therapeutic trait of the prospective child. Sex is considered a therapeutic trait only where prospective parents make abortion decisions based on the incidence of sexually-linked genetic diseases.[53] Again, the question here whether it is ethically acceptable to allow prospective parents to choose to have an abortion based solely on the sex of the fetus.

Abortion based on the sex of the fetus is a problem that is faced by countries and cultures which still recognize beliefs that male children are more "valuable" than female children.[54] This view is not as pervasive in American culture as it is in older cultures. However, as more pre-natal genetic screening is performed in the United States we will have to confront this issue directly.

Sex-selection is seen as ethically troubling for two reasons. The first is that these decisions have the potential to affect the ratio of the sexes.[55] In a "perfect" situation, the division between males and females would be 50:50. If sex selection were allowed as a reason for abortion, this ratio could be affected to such a degree that it could influence fertility rates.[56] The exact effects of such a situation are difficult to measure. However, this is not the type of atmosphere we necessarily want to foster by allowing sex-selection.

The second argument against sex-selection is that it can affect birth order.[57] Studies have shown that most prospective parents prefer to have their first born be a male.[58] Studies have also shown that the first born child is more likely to be successful than any other subsequent child. If couples choose to have abortions of female first born children, this could severely influence the equality of the sexes.[59]

Sex-selection is generally regarded as more acceptable where parents make sex based abortion decisions in an effort to produce a gender neutral family.[60]

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[53] CHADWICK, *supra* note 40, at 99-101. Sex-linked genetic diseases are generally seen in male children because they inherit one X chromosome from each parent. An example of a sex-linked genetic disease is hemophilia. *Id.* at 127. *See also* Wertz, *supra* note 2.

[54] *See generally* Wertz, *supra* note 2 ,at 1429-36.

[55] Patricia Bayer Richard, *The Tailor-Made Child: Implications for Women and the State, in* EXPECTING TROUBLE: SURROGACY, FETAL ABUSE AND NEW REPRODUCTIVE TECHNOLOGIES 14 (Patricia Boling ed. 1995).

[56] *Id.*

[57] *Id.*; CHADWICK, *supra* note 40, at 128-31.

[58] *See* Wertz, *supra* note 2, at 1429.

[59] At least one author believes that choosing to have males as the first-born child would reinforce the view of women having a dependant position in society. *See* CHADWICK, *supra* note 40, at 131.

[60] Wertz reports a study that showed that thirty-eight percent of persons polled approved of sex-selection in situations where a couple has had two to three children of one sex and desire to have a child of the opposite sex. *See* Wertz, *supra* note 2, at 1429.

This is often done where parents have had children of the same sex and are desirous of having a gender balanced family. Such choices are ethically acceptable because these decisions work to attempt to balance the gender ratio instead of skewing the same.[61]

B. Cost

The cost of the procedures described in Part II has resulted in these procedures being available mainly to higher socioeconomic groups and those who have health insurance.[62] Amniocentesis and CVS are often covered by health insurance and are even recommended by insurance companies.[63] However, procedures involving IVF are many times more expensive than amniocentesis and CVS and are often not covered under health insurance.[64]

This cost problem has obvious consequences. Absent statutes or regulations providing otherwise, those who have resources will be able to afford to take advantage of pre-natal genetic screening while those with fewer resources will be left out. This situation will work a disadvantage to those who cannot afford screening because it will not allow them to take advantage of technologies which can possibly make their children healthier. The result is a disproportionate share of parents of lower socioeconomic groups bearing a high number of children carrying or affected by genetic diseases. The end result is that the care of many of these children will be left to the state and federal governments.

C. Discrimination/Dehumanization

Another ethical issue that must be confronted is dehumanization. These reproductive technologies will essentially allow parents almost unbridled discretion to choose their children's genetic structure and physical appearance.

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[61]Recently, legislation has been introduced in the U.S. Senate which would ban a physician from performing an abortion with knowledge that the abortion is being performed based solely on the gender of the fetus. S. 316, 104th Cong., Reg. Sess. (1995).

[62]AMA, *supra* note 5, at 633; Harding, *supra* note 27, at 1487; Strong, *supra* note 24, at 1190. *See also* Malinowski, *supra* note 3, at 1446 (discussing the limits of availability of pre-natal genetic screening based on geographic location. The author suggests that these testing procedures are generally only available in communities which have medical facilities which perform research in this area of science).

[63]Amniocentesis ranges in cost from $1,000 to $12,000. Malinowski, *supra* note 3, at 1461. Malinowski points out, however, that insurance companies generally only cover these costs where the procedure is recommended by the patient's physician. This leaves doubt on whether individuals who have no medical reason to obtain pre-natal genetic testing can nonetheless obtain insurance coverage. *Id.*

[64]The average cost of IVF ranges between $7,000 and $8,000 per ovulation. In addition, the average cost for pre-natal genetic screening following IVF ranges between $2,000 and $3,000. Norton, *supra* note 3, at 1597. Because these procedures must often be repeated to obtain positive results, the cost differential is large as compared to amniocentesis and CVS. *Id.* at 1598.

This will not only affect children who are brought to term as a result of selective screening mechanisms, but will also affect those children who are born with diseases that could have been avoided but for their parents' ability to obtain genetic screening.

Children who are born with problems that could have been avoided through selective abortion are likely to be stigmatized by their parents and society.[65] Families may look at these children with a somewhat different view knowing that they are in some way genetically different from others.[66] Society will stigmatize these children by depleting resources available to help them deal with their diseases.[67] If we become more focused on trying to stop these children from being born, it is likely that we will pay less attention to trying to help those with genetic diseases cope with their problems.[68] In essence we will be labeling these children as throwaways that have less "worth" than non-diseased children. The result is that children become nothing more than products of their parents making.[69] The products that parents "accept" are given affection and afforded the best opportunities in life while the "unaccepted" products are thrown away and forgotten. To know of this view is troubling, to accept it is outrageous.

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[65] AMA, *supra* note 5, at 637; Strong, *supra* note 24, at 1190.

[66] Strong suggests that parents of these children will be less likely to accept their children's strengths and weaknesses because of the erosion of the child's personal integrity that results from the parent knowing that their child has a genetic malformity that could have been avoided. Strong, *supra* note 24, at 1190.

[67] The AMA and Strong both discuss the devaluation of children who are born with these genetic malformities. Society may see these children as vestiges of times when genetic screening was not available, while the children may see themselves as detached from a society which has actively attempted to do away with genetic diseases such as theirs. *See generally* Strong, *supra* note 24.

[68] This view stresses that over-emphasis on pre-natal genetic screening is a waste of scarce medical resources. *See* AMA, *supra* note 5, at 636; Norton, *supra* note 3, at 1610.

[69] *See* Strong, *supra* note 24. The view of children as products is described as "biological determinism." Like eugenics, this view stresses the importance of biology as a foundation for all human talents and abilities. Thus, if the biology of the human can be controlled, so too can the end product of that biology, children. This view completely discounts the influences of random mating and environmental factors on reproduction and disease epidemiology. The process of reproduction becomes nothing more than a game which can be manipulated by human intervention. As a result, less respect is given to the children that result from such a game. Proctor, *supra* note 34.

V. LEGAL FRAMEWORK

A. Abortion Related Law

1. Case Law

In *Roe v. Wade*,[70] the Supreme Court recognized the right of a woman to have an abortion.[71] Speaking for the majority, Justice Blackmun stated that the right to privacy rooted in the penumbras of the Bill of Rights was originally recognized by the Court in *Griswold v. Connecticut*.[72] Included within this right lies a woman's right to choose whether to terminate her own pregnancy. However, the Court also recognized that this right to an abortion was not absolute.[73] The Court balanced this right against the state's interests in the protection of the health of the mother and of the potential life of the fetus.[74]

To balance these rights and interests, the Court laid out a framework based on the length of the pregnancy. Because evidence presented to the Court showed that it was safer to have an abortion during the first trimester of pregnancy than it was to carry the child to term, the Court recognized an almost unrestricted right to have an abortion during the first trimester.[75]

The Court held that a state could regulate abortion only if the state could show a compelling state interest for regulation that was "narrowly drawn to express only the legitimate state interests at stake."[76] The Court found that the state's interest in the health of the mother would allow regulation of the right to have an abortion starting at the end of the first trimester, or at viability.[77] At viability, the Court found that the state's interest in the health of the potential child became compelling enough to allow a state to regulate abortion unless the health of the mother was put in jeopardy by the prolonging of the abortion.[78]

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[70] 410 U.S. 113 (1973).

[71] *Id.* at 153.

[72] 381 U.S. 479 (1965).

[73] 410 U.S. 113, 153-54 (1973).

[74] *Id.*

[75] *Id.* at 163.

[76] *Id.* at 155.

[77] *Id.* The court reasoned that the state's interest in protection of the potential life of the fetus became compelling at viability because the fetus has the "capability of meaningful life outside the mother's womb" at this point.

[78] 410 U.S. at 163-64. There is confusion as to whether this language is part of the central holding of *Roe*, due in large part to the procedural posture. The plaintiff in the case was not pregnant at the time the case was heard, her health was not in danger, and she sought declaratory and injunctive relief. *Id.* at 120-22. Therefore, it is difficult to decide whether stated circumstances under which a state must allow a post-viability abortion are central to *Roe*'s holding.

The Court reexamined this framework in *Planned Parenthood v. Casey*.[79] This case involved an analysis of a Pennsylvania statute which placed significant restrictions on a woman's right to an abortion.[80]

Writing for a plurality of the Court in *Casey*, Justice O'Connor rejected the trimester framework laid out in *Roe* and described a new framework based on an undue burden analysis.[81] Before describing this new approach, Justice O'Connor recognized that the central holding of *Roe*, that a woman has a right to have an abortion, was a privacy interest that would still be protected as a Fourteenth Amendment Due Process Clause liberty interest.[82]

The *Casey* opinion recognized that a woman has a right to an abortion without significant interference from the state before viability of the fetus.[83] Viability was defined as "the time at which there is a realistic possibility of maintaining and nourishing a life outside of the womb. . . ."[84] During the period between conception and viability, the state cannot place an undue burden on a woman's right to an abortion.[85] The court defined an undue burden as a ". . . state regulation [that] has the purpose or effect of placing a substantial obstacle in the path of a woman seeking an abortion of a nonviable fetus."[86]

In discussing the state's ability to regulate abortion, the Court stated that "[i]n some broad sense it might be said that a woman who fails to act before viability has consented to the State's intervention on behalf of the developing

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[79] 505 U.S. 833 (1992).

[80] *Id.* at 844.

[81] *Id.* at 876. This part of the opinion was joined by Justice Kennedy and Justice Souter. *Id.* at 841-42. Concurring in the judgment of the Court to uphold *Roe*'s recognition of a woman's right to an abortion, Justice Blackmun wrote to express his opinion that the trimester framework should not be disturbed. 505 U.S. at 934 (Blackmun, J., concurring).

[82] *Id.* at 846. The Court recognized that "[t]hese matters, involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment. . . ." *Id.* at 851.

[83] *Id.* at 846.

[84] 505 U.S. at 870. The point of viability has been one of much discussion since the *Roe* decision. At the time of *Roe*, the Court determined that viability was at the end of the second trimester, about twenty-four to twenty-eight weeks. In part, *Casey* overturned the trimester approach of *Roe* because medical technology had pushed viability back even further. In Webster v. Reproductive Health Services, 492 U.S. 490 (1989). The Court upheld a Missouri statute which declared a presumption that a fetus was viable after the twentieth week. For purposes of this paper, viability will be presumed to occur at the twentieth week of gestation. *See also* Agota Peterfy, *Fetal Viability as a Threshold to Personhood*, 16 J. LEGAL MED. 607, 607-16 (1995).

[85] 505 U.S. 878.

[86] *Id.* at 877.

child."[87] Thus, the Court recognized that after viability, a state's interest in the potential life of the fetus and maternal health allow a state to regulate the right to an abortion. As in *Roe*, the Court recognized a state's ability to heavily regulate abortion, even to the point of proscription, after the point of viability of the fetus. Again, the Court recognized an exception to this rule where the health of the mother was in question if the pregnancy was continued.[88]

The legal framework laid out in *Roe* and *Casey* clearly allows selective abortion based on pre-natal genetic screening procedures. Potential parents can have these procedures performed and make an abortion decision well before viability of the fetus. Because the Supreme Court recognizes an almost unqualified right to an abortion before viability, potential parents can exercise this option notwithstanding their reason for doing so. CVS is generally performed before the tenth week of pregnancy. Because results from this test can be returned soon after it is performed,[89] potential parents are left with at least eight weeks to exercise their option to an abortion before the fetus is viable. IVF followed by pre-natal genetic screening allows the abortion decision (discard of the zygote) to be made even before the zygote is implanted into a woman's uterus.[90] Because of the crude state of development of the zygote, the state interest in potential life is less than where the pre-natal genetic screening is performed on a fetus *in utero*.[91] Therefore, the Roe and Casey decisions have even less of an impact on selective abortion decisions made in conjunction with IVF procedures.

The real problem in this area is with amniocentesis. This procedure cannot be performed until sometime between the first and second trimester of pregnancy.[92] Once the test is performed, it often takes up to two or three weeks to obtain the results.[93] With this in mind, it is easy to see how *Roe* and *Casey* could be implicated. For example, a woman who waits until her eighteenth or nineteenth week of pregnancy to have this procedure may not get her results back until almost the twenty-first or twenty-second week of pregnancy. What if the tests show that the child has a severe genetic deformity and that the true

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[87] *Id.* at 870.

[88] *Id.* at 879.

[89] *See* Kolata, *supra* note 10.

[90] *See* Norton, *supra* note 3.

[91] *See* Davis v. Davis, 842 S.W.2d 588 (Tenn. 1992). In this case, the Tennessee Supreme Court tackled the issue of what to do with a number of frozen "preembryos" that resulted from a couple who had gone through a divorce. The court found that the preembryos were not quite persons and were not quite property. However, the court found that these preembryos deserved "special respect because of their potential for human life." *Id.* at 597. This decision makes clear that these preembryos occupy a position inferior to that of embryos *in utero*.

[92] Laurence E. Karp, *The Prenatal Diagnosis of Genetic Disease, in* BIOMEDICAL ETHICS 458 (Thomas A. Mappes & Jane S. Zembaty eds. 1981).

[93] *Id.*

gestational age of the child puts it past the point of viability? This is a problem that is likely to occur.

Casey states that the state has the power to regulate abortion past the point of viability of the fetus. The Court allows the states to regulate abortion to the point where there can be an absolute post-viability ban on the procedure except in cases where the health of the fetus or the health of the mother would be implicated by prolonging the pregnancy.[94] To determine the outcome of this problem, we have to consider state abortion statutes.

2. Statutory Law

a. State Abortion Statutes

There are two general types of state statutes dealing with post-viability abortions. Some states allow a post-viability abortion where a physician certifies that the health of the fetus or health of the mother is endangered.[95] Others allow a post-viability abortion only where the health of the mother is endangered by the continued pregnancy.[96] However, it is unclear whether either of these formulations would allow a post-viability abortion where the genetic screening performed as a result of amniocentesis shows a genetic defect in the fetus.

Those statutes which take the health of the fetus into account do not discuss the quality of life the fetus will have if it is carried to term. A genetic disease like Down's syndrome is a perfect example. Clearly, a child born with Down's syndrome would be born healthy in the sense that substantial life saving techniques would not have to be used to keep the child alive. However, it is also clear that the quality of life a child with such a disease would enjoy would be implicated. The defining line of viability works an evil in this situation. The law allows a woman to have an abortion for a child diseased with Down's Syndrome before viability but does not allow the same option after viability, even though the potential child's quality of life is exactly the same in both circumstances. This also represents a slippery slope because this can also be used to argue that viability is an imaginary line that does not really mean much because, regardless of the reason for choosing an abortion, the child's potential quality of life is the same whether the choice is made before viability or after viability.

The challenge here is for states to pass legislation that will allow post-viability abortions in situations where the health of the fetus or the quality of life of the fetus is seriously endangered while not opening a window to allow

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[94] Planned Parenthood v. Casey, 505 U.S. at 871-73.

[95] KAN. STAT. ANN. § 65-6703 (1992); MD. CODE ANN., HEALTH-GEN. § 20-209 (Supp. 1995).

[96] CAL. HEALTH & SAFETY CODE § 123405(c)(1) (Deering Supp. 1995); FLA. STAT. ANN. § 390.001(2)(a) (West 1996); MO. ANN. STAT. § 188.030(1) (Vernon 1983).

post-viability abortions for trivial reasons.[97] To guard against the slippery slope, states must pass statutes which precisely define the situations in which a woman can have a post-viability abortion. Words like "genetic defect," "fetal abnormality," and "severe" must be clearly defined so that potential parents can be clear as to under what circumstances a post-viability abortion will be allowed. As pre-natal genetic screening increases in application, issues pressing the line of viability will increase in frequency. To handle these situations, states must be able to think prospectively and adequately define under what circumstances a post-viability abortion will be allowed.[98]

b. Partial Birth Abortion Legislation

Recently, Congress passed legislation aimed at ending the availability of post-viability abortions known as partial birth abortions. In his veto message, President Clinton stated that he could not accept this bill because it did not make adequate exceptions for situations where the health of the mother was endangered by a continued pregnancy.[99] This legislation did not consider the health of the fetus as an exception to the ban on partial birth abortions. The language of *Roe* and *Casey* which implores states to take the health of the mother and the health of the fetus into consideration in allowing post-viability abortions has been ignored once more. Although there is wide latitude for regulation of abortions after viability, legislators cannot ignore the Supreme Court decisions on point. For if they do, such enactments will be extensively litigated before ever being executed.[100]

B. What if Roe Was Overturned?

Another question that is important here is what would happen if *Roe* and its progeny were overturned by a future, more conservative Court. If this occurs,

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[97]The author defines "trivial reasons" as having an abortion for non-therapeutic reasons or having an abortion for minor genetic defects or susceptibilities that can either be controlled after birth or do not endanger the health and welfare of the child to any substantial degree.

[98]Without precise draftsmanship, such statutes will likely be litigated under theories of overbreadth and vagueness.

[99]S. 939, 104th Cong., Reg. Sess. (1995); H.R. 1833, 104th Cong., Reg. Sess. (1995). This bill was presented to the President after a House vote on March 27, 1996 adopting the Senate version of the bill. The bill, named the "Partial Birth Abortion Ban," was vetoed by President Clinton on April 10, 1996. Michelle Morgan, *Clinton Vetoes Partial-Birth Abortion Ban*, Apr. 10, 1996, *available in* WL 8785434.

Legislation is also pending in several states concerning bans on partial birth abortions. *See* A.B. 2984, Gen. Sess. (Cal. 1995); S.B. 6901, 219th Gen. Assem., 2nd Reg. Sess. (N.Y. 1995); H.B. 206, 52nd Leg., Gen. Sess. (Utah 1996).

[100]There is a question here as to whether the language of *Roe* and *Casey* discussing post-viability abortions is applicable to Congress. Both of the aforementioned cases were attempts by state legislatures to regulate abortion. Here, the issue is the lengths to which the *federal* legislature can go in regulating post-viability abortions.

each state will then have the awesome responsibility of deciding when and under what circumstances it will allow an abortion, if it will allow an abortion at all.[101] Again, states will have to adequately define what is meant by terms such as "normal," "abnormal," "defect," and "severe" if they choose to regulate abortion. In addition, such a situation would invite a type of "forum shopping." A pregnant woman may have to read or become familiar with the laws of several states in determining where she can go to have an abortion.[102] This state of affairs would no doubt lead to women intentionally traveling to certain states for the sole purpose of obtaining an abortion. This could lead to a reduction in the freedom to have an abortion, as no state is likely to want to induce women to travel there only to terminate their pregnancies.[103]

C. Procreative Freedom

Pre-natal genetic screening also touches the right to procreative freedom. The Supreme Court began issuing decisions in the 1920's which ultimately recognized a right to procreative freedom protected as a liberty interest under the Fourteenth Amendment's Due Process Clause.[104] However, the case that ultimately led to an expansion of the rights of procreation and marriage was handed down in the 1965 case of *Griswold v. Connecticut*.[105]

In *Griswold*, a plurality of the Court recognized a right to privacy that was deemed a fundamental right. Justice Douglas explained that this right was not express in the language of the Constitution. Rather, it emanated from a penumbra of rights created by the express words of the specific guarantees found in the Bill of Rights.[106] Justice Douglas concluded by stating that this

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[101] Robertson, *The Potential Impact of the Human Genome Project on Procreative Liberty*, *supra* note 47.

[102] This decision would take into account facts such as the gestational age of the fetus and the reason for termination of the pregnancy.

[103] It is likely that no state will wish to be labeled as an "abortion state."

[104] These decisions started with Meyer v. Nebraska, 262 U.S. 390 (1923). In that case, the Court commented on the meaning of "liberty" in the context of the Fourteenth Amendment stating that "without doubt, it denotes not merely freedom from bodily restraint but also the right of the individual to . . . marry, establish a home and bring up children. . . ." *Id.* at 399. The Court's next decision came in Pierce v. Society of Sisters, 268 U.S. 510, 534-35 (1925), where the Court recognized the " liberty of parents and guardians to direct the upbringing and education of children under their control." In 1961, Justice Harlan stated, "[c]ertainly the safeguarding of the home does not follow merely from the sanctity of property rights. The home derives its pre-eminence as the seat of family life. And the integrity of that life is something so fundamental that it has been found to draw to its protection the principles of more than one explicitly granted Constitutional right. . . . Of this whole 'private realm' of family life it is difficult to imagine what is more private or more intimate than a husband and wife's marital relations. Poe v. Ullman, 367 U.S. 497, 551-52 (1961) (Harlan, J., dissenting).

[105] 381 U.S. 479 (1965).

[106] *Id.* at 484-86.

penumbra was large enough to cover the rights of privacy within the marital relationship.[107] Justice Goldberg concurred in Justice Douglas' opinion, but saw the right to privacy as an emanation from the Ninth Amendment. He wrote that the list of guarantees found in the first eight amendments was not exhaustive of the rights guaranteed the people by the Constitution. Rather, he believed that the Ninth Amendment protected other non-express rights that were seen as "fundamental [to] our entire civilization."[108] He found marriage to be a "fundamental personal right . . . protected from abridgement by the Government though not specifically mentioned in the Constitution."[109]

These formulations resulted in the decision in *Eisenstadt v. Baird*[110] which specifically recognized the right of procreative freedom. Speaking for the majority, Justice Brennan wrote, "[i]f the right of privacy means anything, it is the right of the *individual*, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child."[111] This language shows that the Supreme Court recognized an individual's right to make decisions as to the terms under which he or she would procreate. This opened the door for the decision in *Roe* to specifically recognize a woman's right to obtain an abortion.

The decision of whether to carry a child to term or obtain an abortion is clearly within the procreational freedom guaranteed by the aforementioned Court decisions. An embryo or fetus is an extension or a result of the privacy guaranteed in *Griswold* and *Eisenstadt*. If the Court recognizes the freedom of individuals to make their own autonomous decisions on whether to "bear or beget" a child, the decisions made by parents as a result of pre-natal genetic screening fall within the realm of these protected freedoms. Absent overriding considerations, such as those discussed in *Roe* and *Casey*, parents have wide latitude in the freedom to decide whether to have an abortion or to carry an embryo or fetus to term.

VI. CONCLUSION

This paper has discussed a number of important ethical and legal issues surrounding pre-natal genetic screening technologies. As this technology progresses towards the goal of a complete map of the human genome, the law

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[107]Specifically, Justice Douglas asked, "[w]ould we allow the police to search the sacred precincts of marital bedrooms for telltale signs of the use of contraceptives? The very idea is repulsive to the notions of privacy surrounding the marital relationship." *Id.* at 485-86.

[108]*Id.* at 496.

[109]381 U.S. at 496.

[110]405 U.S. 438 (1972).

[111]*Id.* at 453. In its opinion, the Court also made reference to Stanley v. Georgia, 394 U.S. 557, 564 (1969) (recognizing a fundamental right to be free from "unwanted governmental intrusions into one's privacy"), and Skinner v. Oklahoma, 316 U.S. 535, 541 (1942) (recognizing that the right to procreate is a "basic civil right of man").

will eventually have to answer many of the issues raised in this discussion. State or federal legislatures will have to reconsider their law in light of the array of choices that these testing procedures will soon offer. In particular, legislatures must reexamine their abortion statutes and create law that can cope with issues such as post-viability abortions. In addition, states may also want to restrict the amount of choices available to potential parents by directly regulating the use of pre-natal genetic screening. However, the states must be careful that they do not stifle the rights guaranteed in decisions like *Roe*, *Casey*, and *Griswold*.

Professional associations should begin regulating the types of pre-natal genetic screening services that genetic counselors and physicians may offer. The amount of information available to prospective parents, if used inappropriately, can lead to disastrous results such as sex-selection, eugenics and severe discrimination. These professional bodies should have open discussions on these issues and come to resolutions as to what types of services are acceptable to the majority of practitioners. Although these regulations will most likely not have the effect of law, they will provide at least some guidance where there currently is none.

History has shown that attempts at eugenic control can have disastrous results. To avoid these results, professional bodies and legislatures must discuss these issues and come to binding resolutions. The law must keep pace with science.